

Fargo Session – Written Feedback

1. In what ways do you find information about programs and services available to you and your child?
 - Books
 - internet
 - papers
 - DD case manager
 - Easter Seals
 - School
 - South East Human Service Center – Barb Stanton
 - Cass Public Health – Jo Lawrence (more than one mentioned her)
 - School resources
 - through other people
 - agencies
 - Family to Family network
 - PATH, pediatrician
 - other parents
 - Beth Schable – infant development
2. Who is the service provider who primarily coordinates care for your child? (by title or profession)
 - me (6)
 - school special needs director
 - Kathy Williams – Jefferson elementary
 - Jo Lawrence – Cass County Public Health
 - Anne Carlson
 - myself and the father
3. What other health care professionals or service providers assist in organizing or coordinating care for your child?
 - Dr. Clutter (PCP)
 - me
 - school therapists
 - Jo Lawrence@ Cass Public Health
 - Shriners, Dr. Patrick Well (Meritcare Southwest Clinic)
 - Southeast Human Services
 - ARC
 - Dr. Welle, Meritcare
 - Andrea Schoeder, CLS (Community Living Services)
 - pediatrician
 - Cass County Health Services Coordinator
 - pediatrician – Dr. Blehne
 - Ortho – Dr. Klava
 - Shriners Hospital
 - Therapist

4. What do you like about the way your child's care is coordinated?
 - case manager and Medicaid that paid
 - Macy and I are in the center
 - the school is open to all ideas and suggestions to help my son learn and become a better person
 - Jo is absolutely wonderful about directing us to where we need to go
 - all in one place
 - I am in control – otherwise it can be very difficult at times
 - pediatrician, school and speech therapist exchange info.
5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?
 - 1, 5 (because I do the best I can), 2.5, 2, 2, 4, 5, 4, 4
6. What methods are in place to help assure quality care for your child?
 - Me
 - School, DD Case mgr., Easter Seals
 - My determination, assistance from Jo Lawrence, Kathy Williams and Barb Stanton
 - there are no methods
 - me and my husband
 - follow up with professionals
7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?
 - Shriners, experience, 2nd opinion, least invasive treatment
 - no (2)
 - Gillette Children's Hospital – our pediatric neurologist left Meritcare
 - yes – Shriners Hospital, her lets – Hennepin Co. Hospital, Minneapolis for a sleep clinic
 - Shriners – for prosthetic devices and equipment
 - Yes, FL massage therapy
 - Allergis – unique place in LaCrosse Wisconsin
8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?
 - educational needs
 - Early childhood intervention came into my home weekly for speech and OT from age of 2 till 3 then helped transition to special ed public preschool
 - my DD case mgr. at Southeast has been a good resource
 - none, not at all to my knowledge (4)
 - Medicaid, respite from Easter Seals

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

- none
- none
- MA
- none
- Medicaid
- none

10. Have you ever been denied health care services because of financial barriers?

- no
- no
- yes
- no
- No – I don't care what the cost, whatever I need for my son
- denial coverage
- yes – speech therapy

11. What one recommendation do you have for improving the care provided for your child and family?

- Emotional needs are not treated as part of program, both for parents and children
- Better flow of info between all those working with her, and better info on what services and financial assistance are available to us.
- Child care is a huge issue – need grants for child care
- One agency separate from other insurance, hospital or Southeast, and one person or agency that knows about all the services
- Networks within communities
- There needs to be a network setup to help direct people/families on where to go for services, financial assistance, etc. (support groups, play dates)
- Be open to natural medicine (supplements, massage)
- Activities, child care (educated)
- Include parents so we are best informed about our child's needs
- Have all the services available in one place
- pay for education for parents